

STATEMENT BY

SENATOR JOHN H. CHAFEE

FEBRUARY 27, 1984

HEARINGS ON S, 2053

SUBCOMMITTEE ON HEALTH

MR. CHAIRMAN, I WOULD LIKE TO THANK ALL OF THOSE WHO HAVE COME HERE TODAY TO PARTICIPATE IN THESE HEARINGS. MOST NOTABLY, I THANK CHRIS CRADDY, WHO LIVED FOR MANY YEARS IN A LARGE INSTITUTION IN MY OWN HOME STATE OF RHODE ISLAND, AND NOW LIVES IN A COMMUNITY-BASED HOME. CHRIS WILL SHARE WITH US HER PERSONAL FEELINGS ABOUT LIFE IN THIS VERY DIFFERENT SETTING.

WE WILL ALSO HEAR FROM EXPERTS WHO ARE INVOLVED IN THE CARE OF THE SEVERELY DISABLED AND RETARDED BOTH IN LARGE INSTITUTIONS AND COMMUNITY-BASED HOMES, AS WELL AS SEVERAL PARENTS OF RETARDED OR DISABLED INDIVIDUALS.

SOME TIME AGO, I READ SOMETHING THAT I WOULD LIKE TO SHARE WITH YOU TODAY:

THE SEVEN STEPS TO STAGNATION: 1.

WE'VE NEVER DONE IT THAT WAY

2, WE'RE NOT READY FOR THAT YET

3, WE'RE DOING ALL RIGHT WITHOUT IT

4, WE TRIED IT ONCE AND IT DIDN'T WORK OUT

5, IT COSTS TOO MUCH

6, THAT'S NOT OUR RESPONSIBILITY

7, IT WON'T WORK

THIS BILL GIVES US THE OPPORTUNITY TO TAKE POSITIVE ACTIONS ON BEHALF OF THOSE WHO MOST NEED OUR HELP. THESE HEARINGS PROVIDE US WITH A LONG OVERDUE FORUM IN WHICH WE CAN CLOSELY SCRUTINIZE THE CURRENT SYSTEM OF CARE AND DETERMINE HOW IT CAN BE IMPROVED TO BENEFIT THOSE WHO NEED IT MOST,

THIS LEGISLATION IS HIGHLY CONTROVERSIAL AND EVOKES TREMENDOUS EMOTION. IT IS CRUCIAL TO BEAR IN MIND THAT WE ALL SHARE A COMMON PURPOSE — TO PROVIDE THE BEST POSSIBLE CARE TO OUR RETARDED AND DISABLED CITIZENS WHO ARE NOT ABLE TO CARE FOR THEMSELVES. OUR GOAL TODAY IS TO DETERMINE HOW THIS PURPOSE CAN BEST BE ACCOMPLISHED.

SINCE I INTRODUCED THIS BILL LAST NOVEMBER, I HAVE RECEIVED QUESTIONS ABOUT THE STABILITY OF GROUP HOMES, THE ADVISABILITY OF THE 10-15 YEAR SHIFT OF FEDERAL FUNDS TO COMMUNITY PROGRAMS FORM LARGER FACILITIES, THE ELIGIBILITY REQUIREMENTS OF PATIENTS, THE COST, AND MOST IMPORTANT, HOW THE STATES WILL BE ABLE TO DEVELOP VIABLE COMMUNITY-BASED FACILITIES THAT PROVIDE A HIGH QUALITY OF CARE. I HOPE THAT WE CAN ADDRESS ALL OF THESE QUESTIONS TODAY TO THE SATISFACTION OF EVERYONE WHO HAS EXPRESSED SUCH HEARTFELT INTEREST AND CONCERN.

WE ALL HAVE A TENDENCY TO FEAR THE UNKNOWN. THAT IS WHY WE ARE HERE TODAY — TO EXAMINE THIS IDEA OF GROUP HOMES, WHICH IS NEW, AND DIFFERENT AND UNKNOWN TO MOST OF US. WE ARE HERE TO LEARN FROM THOSE WHO WILL TESTIFY — TO LEARN FROM THEIR KNOWLEDGE AND THEIR EXPERIENCE.

WE SHOULD NOT DENY OUR RETARDED AND DISABLED CITIZENS THE OPPORTUNITY TO GROW AND PARTICIPATE IN THE COMMUNITY BECAUSE OF OUR OWN INABILITY TO GRAPPLE WITH THE UNKNOWN. CONGRESS AND OUR NATION HAVE ALWAYS STRIVED TO BETTER THE CURRENT SITUATION. HOW CAN WE ASK ANY LESS FOR THESE PATIENTS OF INSTITUTIONS.